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Patients, Clients, Consumers, Survivors et al: What's in a Name?

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The Substance Abuse and Mental Health Services Administration (SAMHSA) recently invited a dialog about words that are used for individuals with various forms of mental illness and their treatment.[1] For example, what should we call people with schizophrenia? Patients? Clients? Consumers? Survivors? Schizophrenics? People with schizophrenia? People with lived experience? The words we choose are important, for, as Henry Ward Beecher noted, "words are pegs to hang ideas on."[2]

In deciding what words to use, a logical starting point is to ask what schizophrenia is. The answer, which has become overwhelmingly clear in the past 2 decades, is that schizophrenia is a disease of the brain. It exhibits abnormalities of the structure and function of that organ, just as diabetes does in the pancreas, hepatitis does in the liver, and emphysema does in the lungs. Some skeptics have argued that the brain abnormalities observed in schizophrenia are secondary to medications used to treat the disease, but these same abnormalities are found in patients who have never received treatment. A 2002 article reviews 65 such studies,[3] and at least that number of similar studies have been published in the intervening years. Given these findings, it seems logical to follow medical tradition and call people with such abnormalities people with schizophrenia. And if they have received treatment, they can be called patients.

Given what is now known, why should we use alternate terms such as "client," "consumer," or "survivor"? Where did these terms come from? "Client" was apparently borrowed from Carl Rogers' 1951 book, *Client-Centered Therapy*, which describes a technique of psychotherapy for individuals with disorders other than schizophrenia. Both "consumer" and "survivor" are products of the 1970s, when the medical basis of schizophrenia was less clearly defined. Thomas Szasz claimed that schizophrenia did not even exist, Ronald Laing argued that it was a growth experience, and Ken Kesey popularized the notion that schizophrenia was caused by putting people into mental hospitals. Out of this intellectual mélange emerged groups such as the Mental Patients Liberation Front and the Network Against Psychiatric Assault, and terms such as "consumer" and "survivor" came into use.[4]

"Client" is defined by Webster's dictionary as "a customer," especially of legal or accounting services. It thus implies one who voluntarily seeks services. The term is widely used by psychosocial rehabilitation services, such as clubhouses, where individuals do indeed voluntarily seek services. In that voluntary context, it seems appropriate.

"Consumer" is defined by the dictionary as "one who consumes, spends, wastes or destroys." It has a quintessentially American ring to it, evocative of Walmart and maxed-out visa cards. It conveys the idea that individuals who are receiving psychiatric services should have choices and should participate in the decision making, an important and useful concept insofar as those with schizophrenia are aware of their illness and thus able to make choices. Unfortunately, it is now clear that in approximately half of all individuals with schizophrenia, the disease affects brain areas that govern self-awareness.[5] Such individuals are largely unaware of their own illness, deny that anything is wrong, and refuse all treatment. This condition is well known among neurologists and referred to as anosognosia; we even know the parts of the brain that are affected and cause this deficit. "Consumer" is thus not a useful term for people with schizophrenia because it refers to only the half of individuals with this disease who are aware of their illness and it excludes the others.

"Survivor" is defined in the dictionary as "one who exists after the death of another, or after some event or time." The term is used by psychiatric patients, not like "cancer survivor" but in a more menacing sense like "rape survivor" or "Holocaust survivor." It implies survival of a traumatic event, specifically in this case involuntary treatment for a psychiatric illness. A major goal of the National Association of Psychiatric Survivors, organized in the 1980s, is to abolish all involuntary

treatment. Such a goal ignores the needs of those individuals with schizophrenia who are unaware of their illness and who, because they are not being treated, are regularly victimized and end up homeless and/or incarcerated. Thus, ''survivor,'' like ''consumer,'' applies to only some individuals and is not all-inclusive. To use such terms ignores the needs of those to whom it does not apply and is thus a form of discrimination.

Despite this, ''consumer'' and ''survivor'' have become surprisingly politically correct and have been adopted by government and independent agencies. The federal government under SAMHSA has a National Advisory Council Subcommittee on Consumer/Survivor Issues and uses public funds to support a National Mental Health Consumers' Self-Help Clearinghouse. At the state level are organizations such as the Mental Health Consumer/Survivor Network of Minnesota. The National Alliance on Mental Illness has a Consumer Council. There is even a National Association of Consumer/Survivor Mental Health Administrators under the parent National Association of State Mental Health Program Directors.

The latest term being used for people with schizophrenia and other severe psychiatric disorders is ''people with lived experience,'' sometimes abbreviated ''PWLE.'' It is being increasingly used by groups funded by SAMHSA. For example, the website of the SAMHSA-funded National Empowerment Center states that ''a consumer-driven system means one which is guided by people with a lived experience.''[6] Another SAMHSA-supported program, for mentally ill veterans, claims: ''These activities present new and exciting opportunities for people with lived experience to become actively involved in reshaping policies and practices that impact upon their daily lives.''[7] Similarly, a 2006 article in a rehabilitation journal is titled: ''Recovery from severe mental illness: the lived experience of the initial phase of treatment.''[8]

At first glance, it is unclear what is meant by ''people with lived experience.'' It surely is not meant to distinguish this group of people from people with non-lived experience or from non-people with lived experience. Because all living people have experience, the term seems like a creation of Lewis Carroll. In reading the literature in which ''people with lived experience'' is used, however, it is apparent that most of the time the term is meant to imply that the delusions, hallucinations, and other symptoms experienced by individuals with schizophrenia are merely part of a spectrum of human experience. It is thus an implicit refutation of the medical model of disease. Carried logically forward, it suggests that diabetes is not a disease but merely a ''lived experience'' of having a high blood sugar level. In fact, the underlying intent of using most of these alternate terms for people with schizophrenia is to challenge the idea of schizophrenia as a brain disease.

Using terms for schizophrenia that imply that it is not a disease is also inherently inconsistent at a personal level. Most individuals with schizophrenia, including those promoting terms such as ''people with lived experience,'' are receiving medical disability benefits such as Supplemental Security Income, Social Security Disability Insurance, and veterans disability pensions. They are receiving these benefits because they have been diagnosed as having a disease. Logically, if they do not believe that they really have a disease, they should not apply for, or accept, such benefits. They also should not be eligible for parity under insurance laws because parity refers to being treated equally with other diseases, not with other ''lived experience.''

Thus, to use the term ''people with lived experience'' to refer to people with schizophrenia is inaccurate, contradicted by more than a hundred recent studies that clearly establish schizophrenia as a brain disease. Similarly, the terms ''client,'' ''consumer,'' and ''survivor'' are discriminatory to use as general terms because they exclude the half of individuals with this disease who are unaware of their illness. The clearest and most accurate term to use for people who are afflicted with schizophrenia is ''people with schizophrenia.''

What about the term ''schizophrenic''? Once widely used, it has been prohibited by the SAMHSA word police and by some state departments of mental health that have decreed only ''people first'' terminology to be politically correct. Like ''diabetics,'' ''alcoholics,'' and epileptics,'' ''schizophrenics'' can usefully indicate a group of people with a common condition, and some individuals with schizophrenia refer to themselves this way. Thus, for some, it may be a perfectly acceptable term.

Henceforth, then, I will personally use only terms that are both inclusive of all individuals with schizophrenia and scientifically accurate. And because SAMHSA has opened a public dialog on this issue, this seems like an opportune time for federal agencies to correct their use of improper terminology. Indeed, it seems bizarre for one federal agency—the National Institute of Mental Health (NIMH)—to be supporting research projects to understand the causes of a brain disease that another federal agency—SAMHSA—is describing in discriminatory and misleading terms, especially because both SAMHSA and NIMH are part of the Department of Health and Human Services. Let us then propose that ''client'' be used only in the context of psychosocial rehabilitation services and that ''consumer,'' ''survivor,'' and ''people with lived experience'' be abolished from all federal publications when they are used to refer to people with schizophrenia. They can be consigned to the junk heap of lexicographic history.

References

1. What's in a term? *SAMHSA News.* March/April 2010. http://www.samhsa.gov/samhsaNewsletter/Volume_18_Number_2/TermsWeHear.aspx. Accessed August 16, 2010.

2. Beecher HW. *Proverbs From Plymouth Project.* New York, NY: D. Appleton and Co.; 1887.
3. Torrey EF. Studies of individuals with schizophrenia never treated with antipsychotic medication: a review. *Schizophr Res*. 2002;58:101–115.
4. Rissmiller DJ, Rissmiller JH. Evolution of the antipsychiatry movement into mental health consumerism. *Psychiatr Serv*. 2006;57:863–866.
5. Amador X, David A. *Insight and Psychosis: Awareness of Illness in Schizophrenia and Related Disorders.* 2nd ed, New York, NY: Oxford University Press; 2004.
6. Fisher D. How consumers step up to design a truly recovery-based mental health system. The National Empowerment Center website, http://www.power2u.org/articles/fisher/consumers-step-up.html. Accessed July 8, 2010.
7. Miller LD. Leveling the playing field: practical strategies for increasing veterans' involvement in diversion and reentry programs, the CMHS National GAINS Center newsletter, July 2009, http://www.gainscenter.samhsa.gov/pdfs/veterans/levelingthefield_veterans.pdf. Accessed July 8, 2010.
8. Bradshaw W, Roseborough D, Armour MP. Recovery from severe mental illness: the lived experience of the initial phase of treatment. *Int J Psychosoc Rehabil*. 2006;10:123–131 http://www.psychosocial.com/IJPR_10/Lived_Experience_of_Treatment_Bradshaw.html. Accessed July 8, 2010.